DOCUMENT RESUME

ED 414 682 EC 306 027

AUTHOR	Horsley, Janet W.; Allen, Elizabeth R.; Daniel, Patricia White
TITLE	Nutrition Management of School Age Children with Special Needs: A Resource Manual for School Personnel, Families, and Health Professionals. Second Edition.
INSTITUTION	ERIC Clearinghouse on Disabilities and Gifted Education, Reston, VA.; Virginia State Dept. of Education, Richmond.
SPONS AGENCY	Health Resources and Services Administration (DHHS/PHS), Washington, DC. Maternal and Child Health Bureau.
PUB DATE	1996-00-00
NOTE	100p.
CONTRACT	MCJ-513305
PUB TYPE	Guides - Non-Classroom (055)
EDRS PRICE	MF01/PC04 Plus Postage.
DESCRIPTORS	Case Studies; Cerebral Palsy; Compliance (Legal); Diabetes; *Dietetics; Diseases; Downs Syndrome; Elementary Secondary Education; Individualized Education Programs; *Intervention; Lunch Programs; *Nutrition; *Nutrition Instruction; Seizures; *Special Needs Students; Spina Bifida
IDENTIFIERS	Americans with Disabilities Act 1990; Cystic Fibrosis; National School Lunch and Child Nutrition Act 1975; Phenylketonuria; Rehabilitation Act 1973 (Section 504); Rheumatoid Arthritis

ABSTRACT

This guide is intended to help school personnel facilitate the management of special diets and nutrition education in the school curriculum in accordance with requirements of the National School Lunch Act, the Child Nutrition Act, the Rehabilitation Act of 1973 (Section 504), and the Americans with Disabilities Act of 1990. After the introduction, Section 1 offers an overview of practical interventions during the school day. A chart identifies specific nutritional problems, lists disabling conditions the problem is associated with, and lists suggested interventions. Section 2 addresses dietary considerations of the following specific conditions: cerebral palsy, cystic fibrosis, diabetes mellitus, Down Syndrome, juvenile rheumatoid arthritis, phenylketonuria (PKU), seizure disorders, and spina bifida. This section also considers the related factors of constipation, feeding abnormalities, and tube feeding. Section 3 is on nutrition related goals and objectives in students' individualized education plans (IEP) or Section 504 accommodation plans. Examples and case studies are provided for each of the above listed conditions. Seven appendices include a sample dietary management record, lunch menu ideas for special diets, suggestions for nutritious snacks, possible textural modifications, detail on diet and drugs for juvenile rheumatoid arthritis, possible complications of tube feeding, and guidelines for the PKU diet. (Individual sub-sections contain references.) (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED 414 682

NUTRITION MANAGEMENT OF SCHOOL AGE CHILDREN WITH SPECIAL NEEDS

A RESOURCE MANUAL FOR SCHOOL PERSONNEL, FAMILIES AND HEALTH PROFESSIONALS

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

By: Janet W. Horsley, M.P.H., R.D., C.S.
Elizabeth R. Allen, R.D.
Patricia White Daniel, Ed.D

EC 306427

BEST COPY AVAILABLE

An Interagency Project Between the Virginia Departments of Health and Education

Supported in part by project #MCJ - 513305 from the Maternal and Child Health Program (Title V, Social Security Act), Health Resources and Services Administration, United States Department of Health and Human Services

Second Edition
© 1996
Copyright by
Virginia Department of Health and Virginia Department of Education
All Rights Reserved

TABLE OF CONTENTS

FOREWORD v

ACKNOWLEDGEMENTS vi

INTRODUCTION 1

I. PRACTICAL INTERVENTIONS DURING THE SCHOOL DAY - AN OVERVIEW 3

II. DIETARY CONSIDERATIONS OF SPECIFIC CONDITIONS AND RELATED FACTORS 10

- Cerebral Palsy 11
- Cystic Fibrosis 15
- Diabetes Mellitus 18
- Down Syndrome 23
- Juvenile Rheumatoid Arthritis 25
- Phenylketonuria 28
- Seizure Disorders 32
- Spina Bifida 35
- Constipation 39
- Feeding Abnormalities 43
- Tube Feeding 48

III. INDIVIDUALIZED EDUCATION PROGRAM: NUTRITION GOALS AND OBJECTIVES 53

CASE STUDIES 58

- Cerebral Palsy 58
- Cystic Fibrosis 60
- Diabetes 61
- Down Syndrome 63
- Juvenile Rheumatoid Arthritis 64
- Phenylketonuria 66
- Seizure Disorder 68
- Spina Bifida 70
- Tube Feeding 72

APPENDICES

A. DIETARY MANAGEMENT RECORD 74

B. LUNCH MENU IDEAS FOR SPECIAL DIETS 75

- Low Calorie Diet 77
- High Calorie Diet 78
- High Fiber Diet 79
- Diabetic Diet 80
- Phenylketonuria Diet 81

C. NUTRITIOUS SNACKS 83

- High Calorie Snack Suggestions 84
- Low Calorie Snack Suggestions 85

D. TEXTURAL MODIFICATIONS 86

E. JUVENILE RHEUMATOID ARTHRITIS: DIET AND DRUGS 88

F. COMPLICATIONS OF TUBE FEEDING 91

G. PHENYLKETONURIA (PKU) DIET: FREE FOODS 93

FOREWORD

We are pleased to present this resource manual as a product of the federally funded project, "State Program and Staff Development to Improve Nutrition Services for School Age Children with Handicapping Conditions in Virginia"(1989). This project has served as an exemplary interagency initiative, creating a model for the development of nutrition services for children and youth with special health care needs. This collaborative undertaking has resulted in the marshalling of resources between health and education professionals to expand, develop, and augment nutrition services within the public school systems of Virginia.

Recognizing the nutrition needs of children with disabilities and chronic illnesses, this publication will enable school personnel, parents, nutritionists, and therapists to more effectively manage dietary and special feeding problems. Moreover, through improving the nutrition status of children with special needs, they will benefit from positive health outcomes and a better quality of life.

Randolph L. Gordon, M.D., M.P.H.
State Health Commissioner
Virginia Department of Health

William C. Bosher, Jr., Ed.D.
Superintendent of Public Instruction
Virginia Department of Education

ACKNOWLEDGEMENTS

Appreciation is expressed to individuals in the Virginia Department of Health and Virginia Department of Education who took a special interest in the nutrition grant project which produced the first edition of this manual. Sincerest thanks are extended to Doris Clements, M.S., R.D., Jane Logan, Ph.D., and Marlene Culpepper, M.S., R.D. for their advice, time, and support throughout the project and their many contributions which made this interagency project a reality.

Special thanks are extended to Josephine Cialone, M.S., R.D., C.S., and Harriet Cloud, M.S., R.D. for their expertise in the area of nutrition and feeding disorders of children with disabilities and chronic illnesses. They provided guidance for the development of the second edition of the manual.

Finally, gratitude is expressed to the families of children with special needs who have taught us about the challenges and joys of this field of nutrition.

INTRODUCTION

The purpose of this manual is to assist school personnel to plan nutrition services for students with special needs. The information contained in this manual will facilitate the management of special diets and the expansion of nutrition education in the school curriculum. Information pertaining to the following topics will be discussed:

- **Common Nutrition Problems and Interventions During the School Day;**
- **Dietary Considerations Related to Specific Conditions; and**
- **Nutrition Goals and Objectives for the Individualized Education and 504 Plans.**

Child nutrition programs operate under the **National School Lunch Act** and the **Child Nutrition Act of 1966**. This federal legislation stipulates that in a meal pattern certain types of food substitutions may be made which will allow the program to remain eligible for reimbursement. In response to Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, federal regulations permit food substitutions to accommodate a student with a medical or special dietary need. Students with disabilities requiring special diets must have a written order from a physician which identifies the disability, provides a statement of how the disability affects the diet, and states the dietary changes and suggested meal modifications. The child with special needs who is not identified as a student

with a disability must have a written order from a recognized medical authority (i.e., physician, physician's assistant, nurse practitioner, or other specialist identified by the state) according to federal regulations 7 CFR 210.10.

Child Nutrition Program (CNP) personnel play an important role in the health and physical well-being of the students with chronic illnesses and disabilities. School breakfast and school lunch programs provide nourishing meals and the cafeteria becomes a learning environment for the child with a special feeding or dietary need. Coordination between the CNP personnel, the school staff and the child's family will ensure that the child learns about his nutrition and feeding needs and has a pleasant mealtime experience. Cooperation between the home and school environments will provide consistent support and reinforcement for a successful dietary program.

A dietary management record is available in Appendix A. This may be used by school personnel to outline the dietary program at school, and at home for students with special needs.

I. PRACTICAL INTERVENTIONS DURING THE SCHOOL DAY - AN OVERVIEW

PRACTICAL INTERVENTIONS DURING THE SCHOOL DAY - AN OVERVIEW

Nutrition related problems are medical risk factors for all children, but are especially significant for children who are disabled, chronically ill or developmentally delayed. The inherent nature of a disability or illness places additional stresses on a child's growth and development. Problems include inadequate intake of calories and nutrients, delayed growth, underweight or overweight conditions, dental problems and chronic constipation. Proper nutritional intervention may prevent, control or correct these conditions.

Meeting the nutritional needs of children with special needs is a challenging task and can be accomplished with appropriate education and resource materials available to school personnel. Moreover, coordination with the families and health care providers of these children is essential. Typical nutrition problems, commonly associated conditions, and suggested intervention strategies are provided.

PRACTICAL INTERVENTIONS DURING THE SCHOOL DAY

PROBLEM	POSSIBLE CONDITIONS	SUGGESTED INTERVENTIONS
1. Overweight	Cerebral Palsy Down Syndrome Spina Bifida Developmental Disabilities which lead to inactivity	Weight Control: (See Appendix B. Lunch Menu Ideas for Special Diets) • Use low calorie substitutes. - substitute low fat milk for whole milk - substitute fruit for cookies, cakes, or pies - substitute gelatin, applesauce or low calorie ice treats for ice cream • Use low calorie cooking methods. - serve raw or steamed vegetables instead of those cooked in fat - bake, broil, or stew meats instead of frying - avoid cream sauces, gravies, syrups and sugar - remove all visible fat from meats and skin from chicken • Monitor growth on a regular basis. • Provide group support and nutrition education through a school "weight watchers" group. • Refer to Appendix C. Nutritious Snacks: Low Calorie Suggestions providing a list of snacks less than 100 calories.
2. Underweight	Cerebral Palsy Cystic Fibrosis Children with feeding problems	Weight Gain: (See Appendix B. Lunch Menu Ideas for Special Diets) • Use high calorie and high protein foods to provide nutritious sources for weight gain. - add powdered milk to milk, milkshakes, puddings, custards, cream soups, mashed potatoes, scrambled eggs, meat loaf or cooked cereal - add cheese to sandwiches, meats, potatoes, salads, vegetables, rice, pasta, or cream sauces - serve cottage cheese with crackers, toast, and gelatin salads (many children enjoy it mixed with fruit or fruit cocktail) - mix plain or flavored yogurt with granola, or use in beverages such as a blended shake - add hard boiled eggs to casseroles, sandwich spreads, meat loaf, or salads - boost calories and the protein content of milk or milkshakes by adding instant breakfast mixes

BEST COPY AVAILABLE

PRACTICAL INTERVENTIONS DURING THE SCHOOL DAY

PROBLEM	POSSIBLE CONDITIONS	SUGGESTED INTERVENTIONS
2. Underweight (continued)	Cerebral Palsy Cystic Fibrosis Children with feeding problems	Weight Gain: (See Appendix B. Lunch Menu Ideas for Special Diets) • Add soft or mashed fruit to shakes, yogurt, or pudding to add calories and nutrients to a meal; substitute fruit juice for water when making gelatin; use fruits alone to add calories without protein. • Include high fat foods such as margarine, corn oil, mayonnaise, sour cream, and cream cheese to provide concentrated amounts of calories. All of these may be used as spreads on breads and crackers or added to recipes to increase calories. • Provide snacks for supplemental calories and nutrients; snacks should be spaced appropriately to prevent decreased appetite at mealtime; refer to Appendix C. Nutritious Snacks: High Calorie Suggestions. • Monitor growth on a regular basis. • Ensure that children with cystic fibrosis take enzyme medication with meals and snacks.
3. Constipation	Cerebral Palsy Down Syndrome Spina Bifida	Constipation: (See Appendix B. Lunch Menu Ideas for Special Diets) • Increase fluid sources: - provide water, juices, and milk with meals; - serve foods with a high fluid content (e.g., fruits, yogurt, gelatin, pudding, etc.); - encourage drinking fluids between meals. • Increase the fiber content of meals: - serve whole grain breads; - serve bran cereals for breakfast; - serve fresh fruits and vegetables; - sprinkle unprocessed wheat bran on a variety of dishes. • Provide commercial beverage with fiber (i.e. PediaSure with fiber, Ensure with fiber, Sustacal with fiber, etc.)

PRACTICAL INTERVENTIONS DURING THE SCHOOL DAY

PROBLEM	POSSIBLE CONDITIONS	SUGGESTED INTERVENTIONS
4. Feeding Problems • delayed feeding skills	Cerebral Palsy Developmental Delay Down Syndrome Mental Retardation Spina Bifida	<u>Feeding Problems</u>: (See Appendix D Textural Modifications) • Enlist the help of a speech, occupational, or physical therapist for a feeding evaluation and recommendations for appropriate food textures, positioning techniques, and special equipment.
• poor hand-to-mouth coordination		• Offer foods that adhere to a spoon for self-feeding skill development (e.g. , mashed potatoes, cottage cheese, pudding, etc.).
• difficulty chewing and swallowing		• Offer thickened liquids for excessive fluid loss. • Offer thickened liquids to enhance swallowing and prevent excessive fluid loss.
• poor positioning		• Use special equipment and proper positioning for drinking and swallowing difficulties.
• inappropriate mealtime behaviors		• Provide verbal praise and encouragement for successful attempts at new skills.
5. Dental Caries Gum Disease	All students with special needs and developmental delays are vulnerable to poor dental health especially: Cerebral Palsy Down Syndrome Seizure Disorders	<u>Dental Problems</u>: • Encourage good dental health practices. • Restrict sugar and sweets. • Encourage consumption of fruits and vegetables. • Offer soft foods and modified textures if gums are swollen and chewing is painful (finely chopped or mashed foods may be better tolerated).
6. Drug/Food Interactions	Seizures: Anticonvulsants	<u>Drug/Food Interactions</u>: • Encourage high folate food sources. - dark green, leafy vegetables - whole grains - dried beans and peas - oranges or orange juice

PRACTICAL INTERVENTIONS DURING THE SCHOOL DAY

PROBLEM	POSSIBLE CONDITIONS	SUGGESTED INTERVENTIONS
6. Drug/Food Interactions (continued)	Seizures: Anticonvulsants	Drug/Food Interactions: • Emphasize calcium and vitamin D foods. - milk - cheese - puddings - yogurt • Offer small, frequent feedings if appetite is decreased.
	Children on Bowel Management Programs: Laxatives Bulk Preparations Stimulants Stool Softeners	• Refer to Constipation section. • Incorporate in bowel management program. - fluids - fiber rich foods
	Juvenile Rheumatoid Arthritis	• Refer to Appendix E. Juvenile Rheumatoid Arthritis: Diet and Drugs.
7. Tube Feeding	Cerebral Palsy Cystic Fibrosis	Tube Feeding: • Store and administer tube feeding under sanitary conditions. • Check tube placement before feeding. • Administer feedings at room temperature. • Flush tube with specified volume of lukewarm water after each feeding. • Monitor tolerance of feedings; report problems to family and physician; Refer to Appendix F. Complications of Tube Feeding. • Continue oral-motor stimulation as prescribed by medical team. • Keep emergency supply of feeding on hand at school.
8. Metabolic Disorder*	PKU	• Metabolic Disorder: • Obtain specific diet order from physician and nutritionist. • Obtain list of food substitutions for special occasions (i.e. birthdays, holidays, parties, etc.)

PRACTICAL INTERVENTIONS DURING THE SCHOOL DAY

PROBLEM	POSSIBLE CONDITIONS	SUGGESTED INTERVENTIONS
8. Metabolic Disorder* (continued)	PKU	• Metabolic Disorder: • Teach a section on metabolic disorders to the class for nutrition education and support for the child.

* A metabolic disorder, also called an inborn error of metabolism, is an inherited trait in which the normal processing of nutrients is impaired due to the absence or reduced activity of a specific enzyme. If untreated a child with a metabolic disorder is susceptible to developing conditions which can lead to coma or neurological damage. Many inborn errors of metabolism require specific diets for treatment. PKU is one of the more frequently occurring metabolic disorders.

II. DIETARY CONSIDERATIONS OF SPECIFIC CONDITIONS AND RELATED FACTORS

Special Conditions:

- Cerebral Palsy
- Cystic Fibrosis
- Diabetes Mellitus
- Down Syndrome
- Juvenile Rheumatoid Arthritis
- Phenylketonuria
- Seizure Disorders
- Spina Bifida

Related Factors:

- Constipation
- Feeding Abnormalities
- Tube Feeding

CEREBRAL PALSY

Cerebral Palsy (CP) is a nonprogressive disorder of muscle control which results from an injury to the brain during early development. Problems related to CP vary depending on the severity and complexity of the injury. These problems may include hearing and visual impairments, seizures, learning disabilities or mental retardation and nutrition problems (1).

Children with CP may have multiple nutrition related health problems. These nutrition problems include the following:

- Feeding problems such as poor mouth closure, sucking, swallowing or chewing difficulties, and abnormal reflexes such as a bite reflex, gag reflex or tongue thrust may be present (2).
- Vomiting, aspiration, and refluxing may occur. (Refluxing is bringing the food from the stomach into the esophagus or food pipe.) These problems may cause pneumonia when food is caught in the lungs (3).
- Delayed growth may be related to the severity of the muscle impairment, nutrition disorders and feeding problems (2, 4, 5).
- Dental problems including cavities and gum disease may also complicate feeding difficulties (2).

- Constipation may be caused by abnormal muscle tone, immobility, side effects from medications, decreased activity level, and poor eating habits (2).

Calorie needs for children with CP will vary according to the type and degree of motor dysfunction they are experiencing. Spastic CP causes limited mobility and may result in lower calorie needs. As children with spastic CP grow older, they may have problems with obesity; however, it is not uncommon to see a child with severe spasticity who is underweight. Spasticity is caused by increased muscle tone which may increase the child's need for calories. Children with athetoid CP have continuous involuntary movements. This extra movement causes them to use more calories and raises their daily energy requirements (2, 3, 6). In addition, CP children with feeding problems, as described above, may use extra energy during the feeding process which will affect their calorie needs.

RESOURCES:

United Cerebral Palsy Association
1522 K Street NW, Suite 112
Washington, D.C. 20005-1202
(800) USA-5UCP

National Easter Seals Society
230 West Monroe Street
Chicago, IL 60606-4802
(312) 726-6200

NUTRITION EDUCATION MATERIALS:

- Nutrition Care of Children with Developmental Disabilities (A series of five brochures which provide nutrition information on the following topics.)

  (1) Promoting Weight Gain
  (2) Weight Control for the Overweight Child
  (3) Oral Motor Development and Feeding Techniques
  (4) Management of Constipation
  (5) Meal Planning for the Childhood Years

  United Cerebral Palsy of Greater Birmingham, Inc.
  2430 11th Avenue, North
  Birmingham, AL 35234
  Attention: Tina Shaddix, R.D.
  (205) 251-0165

- Family Education Series: Nutrition for Children with Special Health Care Needs (A complete set or individual topics may be ordered)

  (1) Self-feeding
  (2) Drinking from a Cup
  (3) Weight Gain
  (4) Positioning for Eating
  (5) Chewing
  (6) Preventing Iron Deficiency Anemia
  (7) Fluid Needs
  (8) Relieving Constipation
  (9) Swallowing

  Civitan International Research Center
  Sparks Clinic
  University of Alabama at Birmingham
  SC 313
  Birmingham, AL 35294-0017
  (205) 934-5471

REFERENCES:

1. Shaddix, T.E.: Nutritional implications in children with cerebral palsy. Nutrition Focus 6(2):1-6, 1991.

2. Bandini, L., Patterson, B. and Ekvall, S.W.: Cerebral Palsy. In Ekvall, S.W., ed.: Pediatric Nutrition in Chronic Diseases and Developmental Disorders: Prevention, Assessment and Treatment. New York: Oxford University Press, 1993.

3. Sondheimer, J. M., and Morris, B. A.: Gastroesophageal reflux among severely retarded children. Journal of Pediatrics 94 (5):710-714, 1979.

4. Shapiro, B. K., Green, P., Krick, J., Allen, D., and Capute, A. J.: Growth of severely impaired children: Neurological versus nutritional factors. Developmental Medicine and Child Neurology 28:729-733, 1986.

5. Krick, J., and Van Duyn, M. A .S.: The relationship between oral-motor involvement and growth: A pilot study in a pediatric population with cerebral palsy. Journal of the American Dietetic Association 84 (5):555-559, 1984.

6. Krick, J., Murphy, P., Markham, J., and Shapiro, B.: A proposed formula for calculating energy needs of children with cerebral palsy. Developmental Medicine and Child Neurology. 34:481-487, 1992.

CYSTIC FIBROSIS

Cystic Fibrosis (CF) is an inherited metabolic disorder characterized by the production of mucus which interferes with the function of the lungs and digestive organs. Children with CF are considered to be at high risk for nutrition related health problems because the disease is closely associated with the digestion and absorption of foods and eventually affects the growth, development and health of the child. Nutrition problems associated with CF include:

- poor weight gain and growth related to problems absorbing nutrients and foods;
- malabsorption of fats and proteins due to an inadequate level of enzymes to digest these nutrients;
- high calorie needs due to frequent infections, fevers and labored breathing;
- intolerance of lactose, a sugar found in milk and milk products, which can cause cramping and diarrhea;
- intolerance of simple sugars in advanced stages of the disease which may develop into diabetes; and
- vitamin or mineral deficiencies due to poorly absorbed foods containing important nutrients (1, 2).

Children with CF take enzyme capsules which replace the enzymes needed to digest and absorb food. The capsules should be taken with meals and with snacks. Each child requires different amounts of enzymes depending on his/her individual needs and the content of the meal ingested. In addition to the enzyme therapy, children with CF usually follow a high calorie and high protein diet which may include three meals plus supplemental snacks. Several years ago, fat was restricted from the diet of children with CF; however, now with the improved enzyme therapy, most children with CF can handle moderate to high levels of fat in their diets. Fat is an important part of their diet because it provides high amounts of calories and essential fatty acids which are needed in the body (1, 2).

RESOURCES:

National Chapter
6931 Arlington Road
Bethesda, MD 20814
1-800-FIGHT CF

NUTRITION EDUCATION MATERIALS:

- A Teacher's Guide to Cystic Fibrosis (booklet)
- Living with Cystic Fibrosis: Family Guide to Nutrition (booklet)

Cystic Fibrosis Foundation
6931 Arlington Road
Bethesda, MD 20814
(301) 951-4422 or (800) FIGHT CF

- The Power-Packed Packet. A packet of six handouts for pediatric high protein/ high calorie diets.

- The C. Food Diet: A Way of Living. A videotape for adolescents with cystic fibrosis (1/2" videotape-19 minutes)

  Pediatric Pulmonary Center
  The Children's Hospital
  1600 Seventh Avenue, South
  ACC-620
  Birmingham, AL 35233
  Attention: Nancy Wooldridge, MS, RD
  (205) 939-9583

REFERENCES:

1. Ramsey, B.W., Farrell, P.M., Pencharz, P. and the Consensus Committee: Nutrition assessment and management in cystic fibrosis: A consensus report. American Journal of Clinical Nutrition 55:108-116, 1992.

2. Wooldridge, N.H.: Nutrition management of cystic fibrosis. Nutrition Focus 9(6):1-8, 1994.

DIABETES MELLITUS

Diabetes Mellitus is an endocrine disorder in which the body is unable to properly use sugar to provide energy for the cells of the body. It is caused by a shortage of insulin, a substance which transports blood sugar into the cells. Without adequate amounts of insulin, the blood sugar will rise to high levels. Normal fasting blood sugar levels should be less than 115 mg/dl and after a meal, blood sugar levels should be less than 140 mg/dl. With uncontrolled diabetes, these levels are exceeded.

The two types of diabetes are Type I or insulin-dependent diabetes mellitus (IDDM) which occurs in youth, and Type II or non-insulin-dependent diabetes mellitus (NIDDM) usually appears in middle-aged adults. The main differences between these two types of the disease are that Type I begins abruptly with severe symptoms which require insulin to control; whereas, Type II develops gradually with milder symptoms which can often be controlled by changing the diet and following a weight control program. This manual addresses the nutritional concerns for the school age child with Type I or IDDM.

Early symptoms of IDDM include increased hunger and thirst, excessive urination, weight loss and fatigue. Untreated diabetes causes more severe medical problems (1).

The treatment of IDDM involves medication (insulin), self-monitoring of blood sugar levels, exercise and diet. The diabetic diet is basically a well-balanced diet which restricts foods containing simple sugars, controls fat sources, and provides adequate amounts of complex carbohydrates and proteins for growth and development. The diet should be designed according to the child's age, sex, activity level, growth rate and lifestyle. Calorie levels are calculated to promote normal growth and to prevent excessive weight gain.

There are several methods for teaching children their individualized meal plan. Frequently, dietary principles are taught using an "exchange system" in which foods are grouped according to their similar calorie and nutrient content. The six exchange groups include meats, breads, vegetables, fruits, milk and fats. A meal plan of three meals plus snacks is designed with a specified number of servings from each food exchange group. Effective control of blood sugar is best accomplished through even distribution of a child's calorie intake throughout the day; and meals and snacks should be eaten at regular times each day (1, 2).

The diabetic diet is based on the following dietary principles:

- Concentrated sugars and sweets are usually kept to a minimum. These include candy, sugar, syrup, soft drinks, frosting, pastries, cookies, pies and cakes. Children with good control of their diabetes

may tolerate small amounts of these foods to allow some flexibility in their diet (1-3).

- Artificial sweeteners provide some food options for a child with diabetes and may be used in moderation (1-3).
- Fat sources should be controlled in the diabetic diet. In addition to high blood sugar levels, individuals with diabetes have high fat levels (i.e., cholesterol and triglycerides) in their blood and are at greater risk for developing heart disease in later life. To prevent or control these problems, it is important to decrease saturated fats and cholesterol sources in the diet (e.g., eggs, cream, whole milk products, butter, lard, organ meat, red meat, palm and coconut oils, etc.) (1-3).
- Some research shows that high fiber foods help to control blood sugar and to lower blood cholesterol levels. Soluble fibers found in fruits, legumes and oat products have this effect. A gradual increase of fiber is beneficial. It is generally recommended that blood sugar levels be carefully monitored when making these dietary changes (1-3).
- Snacks are an important part of the diet for many young children with diabetes. The timing of the snacks depends on the child's meal

pattern; the schedule of insulin injections; and the child's exercise pattern. Snacks should be eaten at scheduled times. Extra snacks may be needed prior to vigorous or prolonged exercise (1, 2).

Nutrition education is an essential part of the health care for the child with diabetes. Nutrition goals for the student with diabetes are 1) to control blood sugar levels, 2) to achieve normal growth and development, and 3) to follow a well-balanced program incorporating diet, self-monitoring of blood sugar levels, medication and exercise (1-3).

RESOURCES:

American Diabetes Association
1970 Chain Bridge Road
McLean, VA 22109-0592
(800) 232-3472

Juvenile Diabetes Foundation International
432 Park Avenue South
New York, NY 10016-8013
(800) JDF-CURE

NUTRITION EDUCATION MATERIALS:

- Caring for Children with Diabetes
- Introduction to the Exchange System (video)
- Exchange Lists for Meal Planning
- Healthy Food Choices
- Nutrition Guide for Professionals: Diabetes Education and Meal Planning
- Children With Diabetes

- Family Cookbooks, Volumes I, II, III, and IV
- Teddy Ryder Rides Again (coloring book and story for children)

American Diabetes Association
1970 Chain Bridge Road
McLean, VA 22109-0592
(800) 232-3472

- A Child With Diabetes Is In Your Care (brochure)
- Diet, Exercise, and Diabetes (brochure)
- Monitoring Your Blood Sugar (brochure)
- What You Should Know About Diabetes (brochure)
- Your Child Has Diabetes (brochure)
- Low Blood Sugar Emergencies (brochure)
- Kids, Food & Diabetes Cookbook (book)

Juvenile Diabetes Foundation International
432 Park Avenue South
New York, NY 10016
(800) 223-1138 or
Public Service Information Hotline 9:00 am - 5:00 pm EST
(800) JDF-CURE

REFERENCES:

1. Connell, J.E. and Thomas-Doberson, D.: Nutritional management of children and adolescents with insulin-dependent diabetes mellitus: A review by the Diabetes Care and Education dietetic practice group. Journal of the American Dietetic Association. 91(12): 1556-1564, 1991.

2. Ling, L. and Mosiman, J.: Diabetes. In Queen, P.M. and Lang, C.E., eds.: Handbook of Pediatric Nutrition. Gaithersburg: Aspen Publishers, Inc., 1993.

3. American Diabetes Association: Nutrition recommendations and principles for people with diabetes mellitus. Journal of the American Dietetic Association 94(5): 504-506, 1994.

DOWN SYNDROME

Down Syndrome, also called Trisomy 21, is a syndrome with distinct physical and developmental signs that result from a genetic disorder. Characteristics of Down Syndrome are listed below:

- Mild to moderate mental retardation may cause delays in feeding skill development. Children with Down Syndrome may need therapy and training to attain independent feeding skills (1, 2).
- Low muscle tone may interfere with sucking, swallowing and chewing, and may also contribute to problems with constipation (1, 2).
- Growth retardation and low muscle tone causes these children to be at risk for obesity (1-5). Growth charts for children with Down Syndrome, ages one month to 18 years, have been designed for monitoring their height and weight (3, 4).
- Delayed dental development, structural differences of the mouth, and gum disease may interfere with feeding. Textural changes of foods may help the feeding process (1, 2).
- Congenital heart disease may affect the nutritional needs of the child. Increased calories are often needed until corrective surgery is performed or the heart condition is stable (2).

Nutrition services are important for children with Down Syndrome for assisting with the monitoring of growth, adjusting calorie needs and helping with feeding skill training.

RESOURCES:

Association for Children with Down Syndrome, Inc.
2616 Martin Avenue
Bellmore, NY 11710-3196
(516) 221-4700

National Down Syndrome Congress
1605 Chantilly Drive, Suite 250
Atlanta, GA 30324
(800) 232-6372

National Down Syndrome Society
666 Broadway, Suite 800
New York, NY 10012
(800) 221-4602

REFERENCES:

1. Patterson, B. and Ekvall, S.W.: Down Syndrome. In Ekvall, S.W., ed.: Pediatric Nutrition in Chronic Diseases and Developmental Disorders: Prevention, Assessment, and Treatment. New York: Oxford University Press, 1993.

2. Springer, N.S.: Nutrition Casebook on Developmental Disabilities. New York: Syracuse University Press, 1982.

3. Cronk, C.: Growth in children with Down's Syndrome: Birth to age 3 years. Pediatrics 61(4):546-568, 1978.

4. Cronk, C.E., Crocker, A.C., Pueschel, S.M., Shea, A.M., Zackai, E., Pickens, G., and Reed, R.B.: Growth charts for children with Down Syndrome: One month to 18 years of age. Pediatrics 81(1):102-109, 1988.

5. Cloud, H.H.: Developmental Disabilities. In Queen, P.M and Lang, C.E., eds.: Handbook of Pediatric Nutrition. Gaithersburg: Aspen Publishers, Inc. 1993.

JUVENILE RHEUMATOID ARTHRITIS

Juvenile rheumatoid arthritis (JRA) is also called juvenile arthritis or juvenile chronic arthritis. The cause of this chronic disease is unknown, but genetics and emotional stress seem to be related factors. Symptoms of JRA may include inflammation, heat, pain, swelling and stiffness in one or more joints. There may be periods of disease activity when children have mild to severe symptoms and periods of remission when they are symptom-free (1-3).

There are many fad diets and folk remedies promising quick relief and cures. These diets and remedies offer false hope for those who live with arthritis. Specific nutrition problems which need to be evaluated in children with JRA include the following:

- Poor weight gain is related to many factors such as fevers and inflammation which increase the child's calorie needs. Side effects from medications may decrease appetite. If there is arthritis in the jaw, chewing may be painful, and the child may develop fatigue while eating and refuse food (4, 5).
- Growth failure may be caused by the factors mentioned previously and may be compounded by periods of inflammation or by steroid medications which can impair growth (4, 5). In general, children with JRA are smaller and leaner than their healthy counterparts.

- Anemia in children with JRA may be related to disease activity rather than to iron deficiency states (2, 3, 5).
- Side effects such as vitamin deficiencies, stomach upset, indigestion, altered taste, increased or decreased appetite levels, and water retention caused by medications may result in problems for children with JRA. Many of the medications need to be taken with food or milk to avoid stomach upsets (3). **(Refer to Appendix E. Juvenile Rheumatoid Arthritis: Diet and Drugs.)**
- Obesity may be a problem for a small percentage of children with JRA. This may result from overeating, limited activity levels, or water retention and increased weight gain from steroid medications (2, 5).

Many factors put the child with JRA at risk for nutrition related health problems. Routine nutrition evaluations and dietary counseling are an important part of their health care.

NUTRITION EDUCATION MATERIALS:

- Arthritis Information - Children (#4141)
- Diet - Answers questions about the role of diet in arthritis (#4280)

The Arthritis Foundation
P.O. Box 19000
Drawer A-1
Atlanta, GA 30326

REFERENCES:

1. Gewanter, H.L.: Juvenile arthritis. In Hoekleman, R.A., Blatman, A.S., Friedman, S.B., Nelson, N.M., and Seidel, H.M.: Primary Pediatric Care. 2nd ed. St. Louis: C.V. Mosby Co., 1987.

2. Lovell, D. and Henderson, C.: Juvenile rheumatoid arthritis. In Ekvall, S.W., ed.: Pediatric Nutrition in Chronic Diseases and Developmental Disorders: Prevention, Assessment, and Treatment. New York: Oxford University Press, 1993.

3. Koenning, G.M.: Nutrition management of the child with juvenile rheumatoid arthritis. Topics in Clinical Nutrition 3(3):17-22, 1988.

4. Warady, B.D., McCamman, S.P., and Lindsley, C.B.: Anthropometric assessment of patients with juvenile rheumatoid arthritis. Topics in Clinical Nutrition 4(1):7-14, 1989.

5. Bacon, M.C., White, P.H., Raiten, D.J., et al.: Nutritional status and growth in juvenile rheumatoid arthritis. Seminars in Arthritis and Rheumatism 20(2): 97-106, 1990.

PHENYLKETONURIA

Phenylketonuria (PKU) is an inherited disorder which interferes with a child's ability to handle the building blocks of proteins. Proteins are made of building blocks called amino acids. Phenylalanine (PHE) is an amino acid. A child with PKU cannot process the PHE found in protein foods, and as a result, PHE builds up in the blood stream. Normal blood levels of PHE are within the range of 4 to 10 mg/dl. All children need a certain amount of PHE for growth. When a child with PKU has elevated PHE levels he may appear restless and have a short attention span. High levels of PHE over a long period of time can cause serious problems. If left untreated, PKU can prevent normal brain development and result in mental retardation.

PKU is usually diagnosed at birth through a simple blood test which is part of a routine screen on all newborns. The treatment for PKU is a low PHE diet. Through good dietary control mental retardation will be prevented, and the PKU child can grow and develop normally.

The PKU diet is a low PHE diet and the basic principles are described below:

- High protein foods are not allowed. These include milk, cheese, eggs, meat, fish, chicken, peanut butter, beans, nuts and ice cream.
- Products containing Nutrasweet® or aspartame are not allowed. Nutrasweet® contains PHE.

- Medium protein foods are allowed in controlled amounts. These include fruits, vegetables, fruit/vegetable juices, breads, cereals, crackers, popcorn and special low protein commercial products.
- Certain "free foods" (foods that do not contain PHE) are allowed to provide calories and variety in the PKU child's diet. These foods include soft drinks, lemonade, jelly, gum drops, hard candy and popsicles. **(Refer to Appendix G. Phenylketonuria (PKU) Diet: Free Food List.)**
- Special formulas are used to provide the main source of calories and protein in the diet. These formulas are made without PHE. Examples of these formulas include Phenyl-Free®, Phenex® 1, Phenex® 2, PKU® 1, PKU® 2, Maxamum XP®, Maxamaid XP® and Periflex®.

Each child with PKU has a special diet prescription which gives instructions on how much formula must be consumed and how many milligrams of PHE is allowable each day. As the child with PKU grows, the diet should be adjusted and based on age, growth and PHE levels.

Each child with PKU should have a diet prescription on file at school explaining what foods are allowed and the meal pattern to be followed. Some children with PKU will bring to school their formula and a packed lunch. Others make selections from the school lunch and supplement this with formula.

Depending on the age of the child, assistance and/or supervision may be needed at mealtime in selecting appropriate foods. The school lunch can provide an excellent opportunity for nutrition education for the student with PKU; otherwise, the child with PKU should function as a normal, healthy student in the classroom (1, 2).

RESOURCES:

National Maternal and Child Health Clearinghouse
8201 Greensboro Drive, Suite 600
McLean, VA 22102
(703) 821-8955

NUTRITION EDUCATION MATERIALS:

- Education of students with phenylketonuria (PKU) (booklet - NIH 92-3318)

  National Institute of Child Health and Human Development
  9000 Rockville Pike, Building 31, Room 2A32
  Bethesda, MD 20892
  (301) 496-5133

- A Teacher's Guide to PKU

  Arizona Department of Health Services
  Office of Nutrition Services
  Children's Rehabilitative Services
  1740 West Adams Street
  Phoenix, AZ 85007
  (602) 542-1886

- Low Protein Cookery for PKU (second edition)

  University of Wisconsin Press
  114 North Murray Street
  Madison, WI 53715-1199
  (608) 262-8782

- A Babysitter's Guide to PKU (booklet)
- Chef LoPhe's Phe-Nominal Cookbook (booklet)
- Dental Health in Children with PKU (booklet)
- Finger Foods Are Fun (booklet)
- Games That Teach: Learning By Doing for Preschoolers with PKU (booklet)
- New Parents' Guide to PKU (booklet)

Maternal and Child Health Clearinghouse
8201 Greensboro Drive, Suite 600
McLean, VA 22102-3810
(703) 821-8955

- The Essentials of PKU: An informational pamphlet for young adults with phenylketonuria and their significant others (booklet)
- Making the change from high phe to low phe: Changing recipes to fit your low phenylalanine meal pattern (booklet)

PKU Clinic
CDMRC, WJ-10
University of Washington
Seattle, WA 98195

REFERENCES:

1. Hunt, M. and Berry, H.: Phenylketonuria. In Ekvall, S.W., ed.: Pediatric Nutrition in Chronic Diseases and Developmental Disorders: Prevention, Assessment, and Treatment. New York: Oxford University Press, 1993.

2. Trahms, C.M.: Nutrition education for the child with a metabolic disorder. Nutrition Focus 5(3): 1-6, 1990.

SEIZURE DISORDERS

A seizure is a sudden, involuntary, time-limited alteration of neurological function. Most seizures have no identified cause, but they may be part of a disability or the result of an injury to the brain. Seizures are usually brief, lasting only seconds or minutes. They result in a disorganization of one or more brain functions causing a change in behavior, muscle tone, speech, mood or level of awareness. There are many different types of seizures. Epilepsy is a term which identifies a chronic condition in which the individual has recurring seizures (1).

The primary nutrition problems of children with seizures are related to the side effects of their anticonvulsant medication and the interaction of this medication with foods. These side effects depend on many factors such as the length of time the drug has been taken, combined interactions with other medications, and the child's general nutritional health. Certain anticonvulsants cause drug-nutrient interactions which include:

- changes in appetite levels;
- low levels of folic acid in the blood;
- interference with vitamin D activity which can lead to low levels of calcium in the blood and decreased bone mass; and
- swollen or tender gums which may interfere with feeding (1, 2).

In very specific cases children with seizures may be prescribed a ketogenic diet for the treatment and control of seizures. Usually this diet is prescribed for children with poorly controlled seizures who cannot tolerate the side effects of their seizure medicine.

The ketogenic diet is designed to maintain a state of ketosis which happens when the body relies on fats as a source of energy and produces compounds called ketones. Ketosis has been found to improve seizure control in certain cases. The diet is very high in fat and low in carbohydrates. It is a carefully calculated diet and requires daily monitoring to maintain ketosis. A child on a ketogenic diet should be followed by a registered dietitian and have a prescribed meal plan to follow daily. This meal plan should be on file at the school. Coordination between the child's family, the neurologist, the dietitian, and the school is recommended (1, 3).

RESOURCES:

Epilepsy Foundation
4351 Garden City Drive
Landover, MD 20785
(301) 459-3700

The National Epilepsy Library and Resource Center
4351 Garden City Drive
Landover, MD 20785
(800) EFA-4050

REFERENCES:

1. Ekvall, S.W. and Iannoccone, S.: Epilepsy. In Ekvall, S.W., ed.: Pediatric Nutrition in Chronic Illnesses and Developmental Disorders: Prevention, Assessment, and Treatment. New York: Oxford University Press, 1993.

2. Cloud, H.H.: Developmental disabilities. In Queen, P.M. and Lang, C.E., eds.: Handbook of Pediatric Nutrition. Gaithersburg: Aspen Publishers, Inc., 1993.

3. Gasch, A.T.: Use of the traditional ketogenic diet for treatment of intractable epilepsy. Journal of the American Dietetic Association 90(10):1433-1434, 1990.

SPINA BIFIDA

Spina bifida, also called myelomeningocele and meningomyelocele, is a defect of the spine which is present at the time of birth. In normal development the spinal cord forms in a column along the back and is surrounded by membranes and the bone of the spine. In spina bifida, membranes form a sac on the back. The spinal cord grows into this sac and spinal nerves below the sac are not properly connected to the spinal cord and brain. As a result, there are many problems which may develop. The type and severity of these problems vary depending on the size and location of this sac and the presence of hydrocephalus (fluid on the brain) (1, 2). Certain types of this birth defect are now considered preventable if folic acid is supplemented in the mother's diet prior to conception (2).

Nutrition related health problems which are often seen in children with spina bifida include the following:

- Obesity is a common problem for children with spina bifida because they are often short for their age, and they have a limited activity level which results from partial or complete paralysis in their lower body. Children with spina bifida have lower calorie needs than other children their age which interfere with weight control (1, 4).

- Feeding problems may occur due to a malformation of a part of the brain called the Arnold Chiari malformation. It may cause swallowing problems and reflux (1, 2, 4).
- Urinary tract infections (UTI) are frequent problems. Approximately 95% of children with spina bifida do not have control of their bowel or urinary bladder because nerves controlling these functions are impaired. To prevent UTI, children with spina bifida may be instructed to drink extra fluids and to maintain an acidic urine with prescribed medicines and diet (1-4).
- Bowel management is a problem for children who may not be able to feel that their rectum is full or that they are passing a stool. Bowel management programs are designed to prevent and treat bowel accidents through a combination of diet, toileting habits and medication (1, 3, 5). **(Refer to the section on Constipation.)**
- Skin care is especially important for persons confined to a wheelchair because pressure sores may develop on the skin. If a child with spina bifida has no feeling in his lower body a sore can develop and become infected without the child seeing it or feeling the pain. A well balanced diet is needed to keep skin healthy and to help the healing process (1, 4).

RESOURCES:

Spina Bifida Association of America
4590 MacArthur Boulevard, NW
Suite 250
Washington, DC 20007
(800) 621-3141

NUTRITION EDUCATION MATERIALS:

- Fresh Fruit, Veggies, and Water (bookiet)

  MCH/WIC Nutrition Services
  Division of Maternal and Child Health
  North Dakota State Department of Health
  600 East Boulevard Avenue
  Bismark, ND 58505-0200
  (701) 328-2493

- Family Education Series on Nutrition for Children with Special Health Care Needs:

  (1) Fluid Needs
  (2) Relieving Constipation

  Civitan International Research Center
  Sparks Clinics
  University of Alabama at Birmingham
  SC 313
  Birmingham, AL 35294-0017
  (205) 934-5471

REFERENCES:

1. Brizee, L.: Nutritional concerns associated with spina bifida. Nutrition News: Improvement of Nutrition Services For Children with Handicaps or Chronic Illnesses 3(4): July/August, 1988.

2. Ekvall, S.W.: Myelomeningocele. In Ekvall, S.W., ed.: Pediatric Nutrition in Chronic Illnesses and Developmental Disorders: Prevention, Assessment, and Treatment. New York: Oxford University Press, 1993.

3. Dustrude, A. and Prince, A.: Provision of optimal nutrition care in myelomeningocele. Topics in Clinical Nutrition 5(2):34-37, 1990.

4. Jacobs, R.A., Blyler, E., and Baer, M.T.: Nutrition risk factors in children with myelomeningocele. European Journal of Pediatric Surgery 1: Supplement 1: 22, 1991.

5. Leibold, S., Braun, P., Cole, J. and Peterson, P.: Bowel Continence and Spina Bifida. Spina Bifida Association of America, 1995.

CONSTIPATION

Children with special needs frequently experience problems with constipation. Constipation may be characterized by hard, dry stools which are difficult or painful to pass; infrequent bowel movements; and/or, the passage of small amounts of stool daily without completely emptying the bowel. Constipation may be caused by one or a combination of factors including:

- lack of dietary fiber and fluids;
- abnormal muscle tone (i.e., low tone or spasticity);
- decreased or significantly altered physical activity level;
- irregular bowel patterns or toileting habits;
- behavioral problems such as anxiety or tiredness which may interfere with regular bowel patterns;
- medical conditions causing lack of sensation in the rectum so that the child cannot feel that the rectum is full (i.e., spina bifida, imperforate anus, spinal cord injury, etc.); and
- side effects of medication (1-3).

A successful bowel management program to prevent and/or treat bowel accidents and constipation usually includes a combination of diet, toileting habits and medications.

The dietary recommendation for preventing constipation is to increase fiber and fluid in the diet. Fiber (roughage) is a non-nutritive substance found in foods

which is not digested in the small intestine. Fiber absorbs water and helps to form a larger, softer stool for easier passage through the bowel. It also increases the movement of food through the intestines (3). Fiber and fluid may be added to the diet through a variety of ways depending on the child's feeding skills. Foods with a high fiber content should be incorporated into each meal. Because there is a wide variety of high fiber foods, different textures are available and should be selected according to the child's oral-motor skills.

If a child is unable to manage high fiber foods, unprocessed wheat bran may be added to the diet by mixing it with foods. Wheat bran should be introduced in small amounts and gradually increased in the diet. A good starting point is one teaspoon per day which is slowly advanced or one or two tablespoons daily while monitoring the child's stool pattern. For the best results, the unprocessed wheat bran should be added to food throughout the day, and fluids should also be increased (1-3).

Liquids and/or high fluid foods should be offered frequently during the day. Nutritious fluids such as water, fruit juice and milk are recommended (1-3). Sometimes milk and milk products may cause problems with constipation. If this happens, milk should be used in limited amounts (i.e., approximately 16 ounces daily). Fluids may also be present in the form of foods such as fruit popsicles, fruits, yogurt, pudding and gelatin.

NUTRITION EDUCATION MATERIALS:

- Booklet on Bowel Management

  Patient Education Center
  Medical College of Virginia
  MCV Station, Box F
  Richmond, VA 23298
  (804) 828-2139

- Fresh Fruit, Veggie and Water

  MCH/WIC Nutrition Services
  Division of Maternal and Child Health
  North Dakota State Department of Health
  600 East Boulevard Avenue
  Bismarck, ND 58505-0200
  (701) 328-2493

- Management of Constipation - (brochure)

  United Cerebral Palsy of Greater Birmingham, Inc.
  2430 11th Avenue, North
  Birmingham, AL 35234
  Attention: Tina Shaddix, R.D.
  (205) 251-0165

- Family Education Series on Nutrition for Children with Special Health Care Needs

  (1) Fluid Needs
  (2) Relieving Constipation

  Civitan International Research Center
  Sparks Clinics
  University of Alabama at Birmingham
  SC 313
  Birmingham, AL 35294-0017
  (205) 934-5471

REFERENCES:

1. Feucht, S., ed.: Constipation. Nutrition News: Improvement of Nutrition services for Children with Handicaps or Chronic Illnesses. July/August 2(4), 1987.

2. Leibold, S., Braun, P., Cole, J. and Peterson, P.: Bowel Continence and Spina Bifida. Spina Bifida Association of America, 1995.

3. Ekvall, S.W.: Constipation and fiber. In Ekvall, S.W., ed.: Pediatric Nutrition in Chronic Illnesses and Developmental Disorders: Prevention, Assessment, and Treatment. New York: Oxford University Press, 1993.

FEEDING ABNORMALITIES

Feeding abnormalities resulting from structural problems in the mouth, nervous system impairment, dental or gum disease, or behavioral problems may interfere with a child's ability to eat a balanced diet. Feeding abnormalities are more frequently identified in children with Down Syndrome, cerebral palsy, spina bifida and developmental delay.

There are many factors which make the feeding experience successful and enjoyable. These include the coordination of the tongue, jaw and lips to chew and swallow foods; proper positioning to provide support for the head and body; and the progression of age-appropriate feeding skills for independent self-feeding. In addition, the feeding environment should be relaxing and pleasant so that the child may focus on the task of eating, and enjoy the socialization of the feeding experience (1-4).

Feeding abnormalities include the following problem areas.

- An exaggeration of a normal feeding skill:
  - tonic bite reflex
  - tongue thrust
  - tongue retraction
  - hyperactive gag reflex

- A delay in the normal progression of feeding skills:
  - inability to grasp food or to finger feed
  - difficulty in cup drinking
  - difficulty using a spoon
- Poor coordination of the jaw, lips and tongue for swallowing and chewing:
  - poor lip closure
  - poorly controlled tongue movements
  - poor chewing pattern
- Inability to sit independently in an upright position:
  - poor head control
  - poor trunk control
  - involuntary movements
- Problem behaviors at mealtime:
  - mouth stuffing
  - rumination (the act of bringing food from the stomach into the mouth to chew again)
  - defensiveness during feedings
  - food refusal
  - self-abusive behavior
  - inability to stay on task
  - prolonged feeding periods

Many of these problems will prevent a child from consuming adequate amounts of calories and nutrients; therefore, children with feeding abnormalities are at risk for poor growth and malnutrition.

Children with feeding abnormalities need feeding and nutrition evaluations to identify and correct the specific problems through appropriate interventions. This is best accomplished by a school-based feeding team which may be composed of an occupational therapist, speech therapist, physical therapist, psychologist and nutritionist. Input from the child's parent and teacher is also essential. The evaluation should include a review of motor skills or patterns which interfere with or enhance feeding; positioning at mealtime; sensory patterns which show defensive or receptive behaviors at mealtime; oral-motor skills which control chewing and swallowing; and, the feeding environment. Recommendations should be made about the amount of calories a child needs for growth and development. Textural modifications of foods may be needed to aid in the development of a child's chewing and swallowing skills **(Refer to Appendix D. Textural Modifications.)** Special equipment may be ordered for the development of self-feeding skills and proper positioning of the child. These recommendations should be integrated into a plan to enable the child to 1) receive adequate nourishment for a well-balanced diet, 2) develop self-feeding skills and, 3) enjoy the social interaction of the feeding experience (1-5).

NUTRITION EDUCATION MATERIALS:

- Oral-Motor Development and Feeding - 1986 (brochure)

  United Cerebral Palsy of Greater Birmingham, Inc.
  2430 11th Avenue, North
  Birmingham, AL 35234
  Attention: Tina Shaddix, R.D.
  (205) 251-0165

- Clinical Management of Gastroesophageal Reflux - A Guide for Parents

  Children's Hospital and Medical Center
  Occupational Therapy Division
  P.O. Box C-5371
  Seattle, WA 98105
  (206) 526-2113

- Family Education Series: Nutrition for Children with Special Health Care Needs

  (1) Self-feeding
  (2) Drinking from a Cup
  (3) Positioning for Eating
  (4) Chewing
  (5) Swallowing

  Civitan International Research Center
  Sparks Clinics
  University of Alabama at Birmingham
  SC 313
  Birmingham, AL 35294-0017
  (205) 934-5471

REFERENCES:

1. Cloud, H.: Feeding problems of the child with special health care needs. In Ekvall, S.W., ed.: Pediatric Nutrition in Chronic Illnesses and Developmental Disorders. New York: Oxford University Press, 1993.

2. Lane, S.J., and Cloud, H.H.: Feeding problems and interventions: An interdisciplinary approach. Topics in Clinical Nutrition 3(3):23-32, 1988.

3. Salomon, A.G., and Lieb-Lundell, C.: Identification, evaluation, and management of feeding disorders. In Crump, I.M.: Nutrition and Feeding of the Handicapped Child. Boston: Little, Brown, and Company, 1987.

4. Rokusek, C., and Heinrichs, E., eds.: Nutrition and Feeding for Persons with Special Needs: A Practical Guide and Resource Manual, 2nd Edition. South Dakota University Affiliated Program, University of South Dakota, School of Medicine, and South Dakota Department of Education and Cultural Affairs, Child and Adult Nutrition Services, 1992.

5. Feucht, S.: Guidelines for the use of thickening agents in foods and liquids. Nutrition News: Improvement of Nutritional Services for Children with Handicaps or Chronic Illnesses 3(6), 1988.

TUBE FEEDING

Tube feeding is an alternative route of feeding when feeding by mouth is inadequate or unsuccessful and the gastrointestinal tract is functional. Some children are not able to meet their calorie needs for growth and development by taking food only by mouth. Other children are unable to eat or swallow safely due to problems with reflux (the action of bringing food from the stomach into the esophagus or food pipe); aspiration (inhaling food into the lungs); or, neurological disorders which may interfere with the development of safe and effective feeding and swallowing skills. For nourishment and growth, these children require feeding tubes to transport energy, nutrients and fluids into the stomach or intestinal tract (1-3).

There are several types of tubes and routes of feeding. Three of the more common types of tubes are defined below:

Nasogastric (NG) Tube - is a small flexible tube which is passed from the nose through the throat and into the stomach. This tube is usually selected for short term or temporary use for tube feeding.

Gastrostomy (G) Tube - is a rubber-like tube that is surgically placed through the stomach wall into the stomach. It delivers fluids and formula directly into the stomach. When a gastrostomy tube is put in place, a procedure called a Nissen fundoplication is sometimes performed to decrease problems with refluxing. This is a surgical procedure in which

tissue from the upper part of the stomach is wrapped around the lower end of the esophagus. This creates a smaller opening to prevent food from being brought up from the stomach into the throat. If a child has this procedure, problems with gas building up in the stomach may occur. This can be relieved by releasing air from the tube. A gastrostomy is used for long term tube feeding, but it may be removed if the child becomes able to consume calories and nutrients safely and effectively by mouth and can sustain optimal growth.

Percutaneous Endoscopic Gastrostomy (PEG) - is a modified prodedure for the placement of a gastrostomy tube into the stomach (1).

Button - is a type of feeding device which is used to replace the G tube. The button is a T-shaped plastic device which is placed in the opening of the stomach wall to replace the G-tube. It is shorter than the G-tube and is less noticeable under clothing. The button is inserted by a surgeon and remains in place at all times. When feedings are given a tube is inserted through the button and into the stomach. When feedings are finished, the tube is removed and the button is capped (1).

When a child is fed through a tube over a long period of time, careful consideration should be given to feeding skill development and oral-motor stimulation. Children should learn to associate the feelings of fullness with oral stimulation by using a pacifier or therapeutic exercises during feeding. This feeding program

should be developed with the child's occupational or speech therapist (2, 3).

Tube feedings may be administered by two methods, bolus or drip. A **bolus** feeding is poured into a large syringe which connects to the feeding tube. The flow of the formula is controlled by the size of the tube, the height of the syringe and the thickness of the formula. A **drip** feeding is administered using a commercial feeding pump. The formula is released into the tube by regulating a clamp on the tube. This provides for controlled feedings which may be administered for specific periods. Depending on the child's needs and the type of formula selected, a drip method can be regulated to provide large volumes of formula over a long period, or to provide a very slow administration of formula (1-3).

Intermittent feedings may be administered over a 20 to 30 minute period at scheduled intervals during the day, much like meals. Other children require continuous drip feedings administered 16 to 24 hours throughout the day. Some children will receive continuous tube feedings for 8 to 12 hours at night while they sleep (1).

Tube feeding formulas should be selected based on several factors. The formula should provide adequate nutrition in the form and volume that the child can tolerate; it should be prepared and administered with ease and under hygienic conditions; and, it should be affordable for the family. A tube feeding formula may be homemade from a blenderized recipe or it may be a commercially prepared product (2, 3). Potential problems with a blenderized recipe include inaccurate

mixing of the formula which will alter the nutrients and calorie content of the diet; separation of the semi-solid ingredients from the liquid portion of the formula which will clog the tube; and increased risk of contamination from improper handling and sanitation in the preparation, transport and storage of the formula (3). To prevent these problems, it is preferable to use a commercially prepared product for at least the portion of the feeding administered at school. These products are available in ready-to-feed cans which are easy to handle and to store away from home. Frequently, vitamin/mineral supplements are prescribed with tube feedings. These supplements are usually given at home. Fluid is a very important component of the tube feeding. Specific calculations are used to estimate the fluid needs of a child. Fluid needs are increased during hot weather, periods of fever or episodes of fluid loss from vomiting or diarrhea. Extra fluid may be added to the formula or may be used to flush the tube (2). When a tube-fed child is enrolled in school, instructions should be given for attending to the child's fluid needs. School personnel should also monitor the child for signs of dehydration.

Complications from a tube feeding can usually be avoided or resolved with proper formula selection, careful administration of the formula and monitoring of the child's tolerance. **Appendix F: Complications of Tube Feeding** describes possible problems and solutions. Whenever a problem is identified, the child's parent and physician should be notified.

RESOURCES:

American Society of Parenteral
and Enteral Nutrition (A.S.P.E.N.)
8630 Fenton Street, #412
Silver Spring, MD 20910
(800) 727-4567

NUTRITION EDUCATION MATERIALS:

- Guide to Gastrostomy Tubes and Their Care: A Parent Instruction Manual

  Kluge Children's Rehabilitation Center
  2270 Ivy Road
  Charlottesville, VA 22903

REFERENCES:

1. Paarlberg, J., Atkinson, W., Bella, D. and Kocher, A.: Guide to Gastrostomy Tubes and Their Care: A Parent Instruction Manual. Charlottesville, University of Virginia, 1991.

2. Nardella, M.T.: Practical tips on tube-feeding children. Nutrition Focus 10(2):1-8, 1995.

3. Lingard, C.D.: Enteral nutrition. In Queen, P.M. and Lang, C.E., eds.: Handbook of Pediatric Nutrition. Gaithersburg: Aspen Publishers, Inc., 1993.

III. INDIVIDUALIZED EDUCATION PLAN AND 504 ACCOMMODATION PLAN: NUTRITION GOALS AND OBJECTIVES

IEP NUTRITION RELATED GOALS AND OBJECTIVES

The Individualized Education Plan (IEP) is the management tool for students receiving special education and related services. The IEP is designed to ensure that each student with a disability is provided special education and related services appropriate to his/her learning needs. It sets forth in writing a commitment of resources which are necessary to enable these students to benefit from special education and related services. Further, it is a communication tool to ensure that all service providers have knowledge of the student's academic problems and the services to be provided. In addition, the IEP establishes a system by which families of students with special needs work as part of an interdisciplinary team to develop health related services.

The IEP includes annual goals, short-term objectives and a schedule for evaluation. It is to be reviewed periodically and its provisions revised, when appropriate. A meeting must be held, at least once a year, for this purpose. Participants in the meeting shall include a representative of the local school division, other than the child's teacher, who is qualified to provide or supervise the provision of special education, the child's teacher, one or both of the child's parents, the child when appropriate, and other individuals at the discretion of the parents or the local school division. For example, a nutritionist may be involved when a nutrition problem is identified for a child with special needs.

The IEP provides an ideal tool for integrating nutrition education into the school curriculum.

It is important to note that every student with a chronic illness may not be labeled disabled and, therefore, would not have an IEP. Special consideration is needed to ensure that resources and services will be provided for chronically ill children with special nutritional needs or feeding problems. For example, a student with diabetes will require special dietary considerations during the school day. Nutrition services should be available to this student through a 504 accommodation plan. Feeding or nutrition modifications would be considered "necessary accommodations" for a chronically ill child.

Incorporating nutrition goals and objectives into the education program will facilitate the delivery of services to improve the nutritional status of children with special needs. These goals and objectives will facilitate instruction on dietary needs and compliance.

An outline of IEP goals and special considerations for writing objectives for children with nutrition or feeding problems is provided. This is followed by case studies which describe children with special nutritional problems. Examples of IEP nutrition goals and objectives which may be incorporated into their education plan are included.

IEP NUTRITION RELATED GOALS AND OBJECTIVES

GOALS	CONSIDERATIONS FOR WRITING OBJECTIVES
1. To develop or refine self-feeding skills	
• finger feeding • use of feeding utensils • use of a cup or glass	• identify special feeding equipment and level of assistance needed for practicing skills • consider food texture and consistency changes to facilitate self-feeding and use of utensils • identify positive reinforcement for successful attempts
2. To improve oral-motor function related to eating	
• lip closure: on spoon/fork on cup/glass while chewing at rest • tongue movement (within and outside the mouth) lateralization, elevation and depression • chewing pattern • suck through straw • bite off pieces of food • oral reflexes hyperactive gag, tongue thrust • oral sensitivity hyposensitive hypersensitive	• consider exercises to facilitate oral-motor function and specify frequency and duration of the exercises • consider food texture and consistency changes to facilitate improved oral- motor function • identify positive reinforcement for successful attempts
3. To improve mealtime behaviors	
• inappropriate finger feeding • pace • rumination/regurgitation • food acceptance (textures, types or variety of foods) • neatness • feeding posture/position • self-abusive behavior • staying on task • staying at the table	• identify supervision needed for monitoring mealtime behavior • identify presentation of new foods/textures and situations • identify the appropriate mealtime environment • identify positive reinforcement for appropriate behavior

IEP NUTRITION RELATED GOALS AND OBJECTIVES

GOALS	CONSIDERATIONS FOR WRITING OBJECTIVES
4. To identify and communicate nutrition needs	
• hunger • thirst • food names • food groups • restricted foods • special nutrients (iron rich foods, etc.)	• identify special instruction or learning activities to teach nutritional needs • identify games/exercises for food or nutrient recognition • identify positive reinforcement for correct responses
5. To improve food preparation and mealtime skills	
• open can, box, carton, package • make sandwich • make snack • pour, stir, slice, etc. • set table • clear table • clean table, utensils	• identify practice periods and exercises or steps for skill development • identify supervision needed to monitor skill development • identify positive reinforcement for successful attempts
6. To improve growth rates	
• weight maintenance with continued linear growth • gradual weight loss with continued linear growth • weight gain and linear growth	• identify person(s) responsible for tracking growth • develop a school weight control program • identify dietary supplements and modifications provided by the school and/or the family • identify extra snacks scheduled during the school day • identify positive reinforcers for growth changes
7. To maintain lab data within normal limits*	
• blood glucose levels (Diabetes) • phenylalanine levels (PKU)	• identify a method to obtain and communicate specific lab values • identify methods of monitoring this data

* These are very specific nutrition goals which may not be appropriate for the school to monitor. However, other goals may be written which relate to this data.

Example: For the child with diabetes, the goal is to decrease episodes of hypoglycemia.

CASE STUDY: CEREBRAL PALSY

Jimmy is a nine year old male with quadrispastic cerebral palsy, severe mental retardation and a seizure disorder. He has a history of chronic failure to thrive and constipation. All of his growth parameters are below the fifth percentile. In the past six months, Jimmy has lost two pounds and his seizures were poorly controlled. His weight is now stable and his seizures have decreased after his anticonvulsant medications were adjusted. Jimmy has delayed chewing skills, poor lip closure, and some lateral tongue movements. He requires support for upright sitting. He eats three meals per day with an occasional afternoon snack. He receives the school lunch which is pureed and fed to him. The main concern of both the school and family is Jimmy's underweight condition.

1. **Nutrition Goal:**	**Jimmy will gain weight and continue to grow taller during the school year.**
Objective 1:	**Jimmy will drink at least four ounces of a high calorie and high protein liquid (e.g., instant breakfast mix, Ensure® , Ensure Plus®, etc.) three days per week.**
Objective 2:	**Jimmy will eat his school lunch supplemented with high calorie additives (e.g., margarine, powdered milk, instant breakfast mix, etc.) three days per week.**

2. Nutrition Goal:	Jimmy will demonstrate improved oral-motor skills.
Objective 1:	Jimmy will practice lip closure skills in occupational therapy sessions three times per week.
Objective 2:	Jimmy will practice chewing skills in occupational therapy sessions three times per week.

CASE STUDY: CYSTIC FIBROSIS

(504 Plan*)

Steve is a seven year old male with cystic fibrosis (CF). His weight/height is at the fifth percentile. Steve has lost four pounds since school started. He is hungry all the time and eats well at school. He is enrolled in the school breakfast and lunch programs. He has been complaining of stomach aches and has had to use the bathroom frequently. Steve appears to be self-conscious about taking his enzymes and will often neglect to take them or leave them at home.

1. Nutrition Goal:	**Steve will gain weight and continue to grow taller during the school year.**
Objective 1:	**Steve will take his enzymes at home and at school with meals and with snacks with 90% compliance.**
Objective 2:	**Steve will eat a high calorie snack at least three times per week at mid-morning and mid-afternoon breaks at school.**

* Note: If a child with CF is not enrolled in special education, he/she will not have an individualized education plan. However, he/she would be eligible for a 504 accommodation plan which would identify the health related services he/she needs during the school day. Nutrition goals and objectives may be incorporated in this plan.

CASE STUDY: DIABETES

(504 Plan*)

Ronnie is a nine year old male with insulin dependent diabetes mellitus. He receives insulin injections, and his physician prescribed an 1800 calorie diabetic diet which is composed of three meals and three snacks daily. Ronnie has been growing well and his growth parameters are within normal limits. He is a very active child and participates in physical education activities. He recently started to play on the school soccer team. His blood glucose levels over the past two months have been low, and he has had several hypoglycemic (low blood sugar) reactions at school and at home. Ronnie has an excellent appetite. He buys his lunch at school where his dessert item is substituted with a fruit, but he frequently neglects to eat his snacks when he is involved in other activities. Both his family and his teachers are concerned about his low blood sugar levels and dizzy spells.

1. Nutrition Goal:	**Ronnie will maintain blood glucose levels within normal limits.**
Objective 1:	**Ronnie will eat his between-meal-snacks four out of five times per week without prompting.**
Objective 2:	**Ronnie will carry an extra snack to soccer practice and eat it halfway through the practice session.**
Objective 3:	**Ronnie will report his blood glucose levels to the school nurse every Friday morning with 90% compliance.**

* Note: If a child with diabetes is not enrolled in special education, he/she will not have an individualized education plan. However, he/she would be eligible for a 504 accommodation plan which would identify the health related services he/she needs during the school day. Nutrition goals and objectives may be incorporated in this plan.

CASE STUDY: DOWN SYNDROME

Katie is a six year old obese female with Down Syndrome, a mild ventricular septal defect (congenital heart disease), and chronic constipation. She is on no medications and has no activity restrictions. She is short in stature and her height is in the fifth to tenth percentile range; her weight/height is above the 95th percentile. Katie had a dramatic weight gain of 30 pounds in the past 18 months. She eats three meals and two snacks daily and enjoys extra portions of food at meals. She refuses fresh fruits and vegetables. Katie is sedentary in her free time, but has taken an increased interest in her physical education class this year, particularly dancing and running activities.

1. Nutrition Goal:	**Katie will maintain her weight and continue to grow taller during the school year.**
Objective 1:	**Katie will eat only one serving of each food offered at mealtime during four out of five meals at school.**
Objective 2:	**Katie will participate in running activities or exercises during physical education classes three times per week.**
2. Nutrition Goal:	**Katie will eat a well-balanced diet choosing foods from the five food groups of the food pyramid.**
Objective 1:	**Katie will eat one tablespoon of fruits or vegetables at lunch three times per week.**
Objective 2:	**Katie will be able to identify two new fruits or vegetables per week following nutrition education.**

CASE STUDY: JUVENILE RHEUMATOID ARTHRITIS

(504 Plan*)

Mary is a 13 year old female with juvenile rheumatoid arthritis. She appears small for her age and all her growth parameters are below the tenth percentile on the growth chart. Her medications for arthritis include Naproxen and Methotrexate. Mary walks with a slight limp. Her family reports that Mary is a picky eater and her appetite seems to have decreased over the past six months; consequently, she has lost three pounds since the beginning of the school year. She dislikes most fruits and vegetables. Mary buys her lunch at school, but rarely finishes it. She has recently stopped eating breakfast in the morning and often leaves for school after taking her first dose of medicine. Mary has shown a slight interest in cooking at home and enjoys swimming. Mary appears to be a very self-conscious adolescent and discusses her health status and diet with some difficulty. Mary's parents are concerned about her deteriorating eating habits and are frustrated in their attempts to help her.

1. Nutrition Goal:	**Mary will gain weight and continue to grow taller during the school year.**
Objective 1:	**Mary will bring a high calorie snack from home and eat it during the afternoon break at least four times per week.**

2. **Nutrition Goal:** **Mary will develop an increased interest in her diet as it relates to Juvenile Rheumatoid Arthritis.**

Objective 1: **Mary will eat a meal or drink eight ounces of an instant breakfast mix for breakfast at least four times per week.**

Objective 2: **Mary will take her medication with milk or food at scheduled times with 90% compliance.**

* Note: If a child with juvenile rheumatoid arthritis is not enrolled in special education, he/she will not have an individualized education plan. However, he/she would be eligible for a 504 accommodation plan which would identify the health related services he/she needs during the school day. Nutrition goals and objectives may be incorporated in this plan.

CASE STUDY: PHENYLKETONURIA (PKU)

(504 Plan*)

Robert is a six year old male with PKU. He has an average intelligence and is functioning at or above his age level for all of his skills. Prior to starting school his phenylalanine (PHE) levels were in the normal range. Upon entering school his levels have been elevated and are more frequently above the 20 mg/dl range demonstrating poor control. His current growth parameters are within normal limits. Robert is on a low protein diet and drinks approximately one quart of Phenyl-Free® per day. He brings his lunch from home and brings money to purchase juice at school. A recent problem has been that Robert uses this money to buy potato chips and other restricted foods from a vending machine. He has been know to trade food with other children. His teacher has questions about what foods Robert is allowed to eat during special classroom functions. Robert's mother is interested in Robert taking more responsibility for his diet and purchasing part of his lunch at school.

1.	**Nutrition Goal:**	**Robert will maintain PHE levels within the normal range (4-10 mg/dl).**
	Objective 1:	**Robert will eat his own lunch with no more than one food item traded per week.**
	Objective 2:	**Robert will report his PHE levels to the school nurse once per month with 90% compliance.**

2.	**Nutrition Goal:**	**Robert will learn about PKU and understand the basic rationale for the diet.**
	Objective 1:	**Robert will identify restricted foods on the school lunch menus each week with 90% accuracy.**
	Objective 2:	**Robert will be able to state four "free-foods" which may be eaten as desired.**

* Note: If a child with PKU is not enrolled in special education, he/she will not have an individualized education plan. However, he/she would be eligible for a 504 accommodation plan which would identify the health related services he/she needs during the school day. Nutrition goals and objectives may be incorporated in this plan.

CASE STUDY: SEIZURE DISORDER

Sam is an 11 year old male with a seizure disorder, mild mental retardation and swollen gums. All of his growth parameters are in the 25th to 50th percentile range. His seizures are controlled with anticonvulsant medication. He demonstrates limited chewing movements and his lip closure is developing, yet, he sometimes loses food and fluids during feeding. He has poor hand-to-mouth coordination and needs close supervision and assistance at mealtime. He eats three meals and two or three snacks daily, yet, he rarely finishes his meals because of the length of time required to eat. Sam refuses to drink milk and enjoys sweets. In a recent evaluation, he was found to have made significant progress in his self-help skills.

1. Nutrition Goal:	**Sam will demonstrate improved self-feeding skills.**
Objective 1:	**Sam will be trained to use adaptive feeding equipment in occupational therapy sessions three times per week.**
Objective 2:	**Sam will practice hand-to-mouth coordination exercises using finger foods at snack time twice each week.**

2. Nutrition Goal:	Sam will demonstrate improved oral-motor skills.
Objective 1:	Sam will close his mouth on a spoon without prompting four out of five trials at mealtime.
Objective 2:	Sam will drink thickened liquids to decrease fluid loss during four out of five meals per week.
3. Nutrition Goal:	Sam will increase his intake of milk or milk products during the school year.
Objective 1:	Sam will drink four ounces of milk or eat a milk product (i.e., cheese, cottage cheese, yogurt, pudding, etc.) on his lunch tray three days per week.

CASE STUDY: SPINA BIFIDA

Betsy is a seven year old obese female with spina bifida and mild mental retardation. She has occasional problems with bowel incontinence. She is able to ambulate with braces and a walker, but prefers her wheelchair. Betsy feeds independently but has some choking episodes after eating rapidly when she is unsupervised. Betsy cries when her favorite foods (desserts and candy) are denied, and she has been known to steal food from other children. She eats breakfast and lunch at school. At home she eats an additional breakfast occasionally; she eats dinner, and snacks while watching television in the evening. Betsy responds well to rewards, especially food.

1. Nutrition Goal:	**Betsy will improve her mealtime behaviors.**
Objective 1:	**With supervision, Betsy will eat slower at meals by putting her utensils down on her tray between bites of food during four out of five meals per week.**
Objective 2:	**With supervision, Betsy will eat foods from her plate or tray without taking foods from other children during four out of five meals per week.**

2. Nutrition Goal:	Betsy will maintain her weight as she continues to grow taller during the school year.
Objective 1:	Betsy will eat only three meals per day consisting of breakfast and lunch at school and dinner at home.
Objective 2:	Betsy and her family will participate in the weight management group at school with an 80% attendance rate.
Objective 3:	Betsy will increase her activity level by walking to and from the cafeteria four out of five days per week.

CASE STUDY: TUBE FEEDING

Susie is a seven year old female with athetoid cerebral palsy, profound mental retardation and a history of failure to thrive. She has poor feeding skills and exhausts easily during feedings. Susie has been hospitalized several times during the school year due to recurrent episodes of pneumonia and dehydration. During her last hospitalization she underwent surgery for a gastrostomy tube. Since her surgery, Susie has been gaining weight, growing in height, and has been more alert. She is returning to school where she will be fed twice each day. Her parents will be sending Pediasure®, a commercially prepared product, to school for her feedings. The school staff is receiving training on tube feeding procedures.

1. Nutrition Goal:	**Susie will tolerate her tube feedings administered at school.**
Objective 1:	**Susie will be fed through her gastrostomy tube 240cc (8 ounces) of Pediasure® at 10:00 am and 2:00 pm daily using procedures outlined by her physician.**
Objective 2:	**Susie will receive oral-motor stimulation during her feedings daily.**

APPENDICES

A. Dietary Management Record

B. Lunch Menu Ideas for Special Diets

C. Nutritious Snacks:

High Calorie Suggestions

Low Calorie Suggestions

D. Textural Modifications

E. Juvenile Rheumatoid Arthritis (JRA):
Diet and Drugs

F. Complications of Tube Feeding

G. Phenylketonuria (PKU) Diet: Free Food List

APPENDIX A

DIETARY MANAGEMENT RECORD

STUDENT'S NAME: _____

AGE: _____ GRADE: _____

SPECIAL CONDITION(S):

NUTRITIONAL NEEDS:

SCHOOL PLAN:

HOME PLAN:

APPENDIX B

LUNCH MENU IDEAS FOR SPECIAL DIETS

1. Low Calorie Diet
2. High Calorie Diet
3. High Fiber Diet
4. Diabetic Diet
5. PKU Diet

APPENDIX B

LUNCH MENU IDEAS FOR SPECIAL DIETS

The following lunch menus show simple substitutions that can be made for children on special diets. They are not intended to be guidelines for every student on these particular diets. Each child should have an individualized meal plan. The child's parent and/or physician should be contacted to clarify any questions about the diet.

APPENDIX B

1. LOW CALORIE DIET

The following low calorie menu adaptations would be acceptable for an overweight or obese student. Each child has individual calorie needs according to his/her height, weight, age and activity level. The modified menus presented below are possible suggestions. They **are not** standards to be used for every overweight child.

	Original Menu	Modified Menu for Lower Calories*
Day 1	Oven fried chicken Roll String beans Honey glazed carrots Yellow cake with assorted icing Whole milk	Oven fried chicken (remove skin) Roll String beans Steamed carrots Chilled pears Skim or low fat milk
Day 2	Meat loaf Roll Whipped potatoes Steamed cabbage Brownie Whole milk	Meat loaf Roll Steamed cabbage Tangerine Skim or low fat milk
Day 3	Fish wedge Cornbread Potato barrels Greens Yellow cake with chocolate icing Whole milk	Fish wedge Slice of whole wheat bread Tossed salad Greens Baked apple Skim or low fat milk

* It is recommended not to exceed one teaspoon margarine per meal for a low calorie diet.

APPENDIX B

2. HIGH CALORIE DIET

The following menus have been modified to increase the calorie content for students who are on a diet for weight gain and growth. Calories may be increased by adding proteins, carbohydrates or fats. Experiment with different combinations of food and calorie booster ideas to determine what is well accepted by each individual student.

	Original Menu	Modified Menu to Increase Calories*
Day 1	Fish wedge Roll Mixed vegetables Sliced peaches Whole milk	Fish wedge Roll Mixed vegetables Sliced peaches Spice cake Whole milk with an instant breakfast mix added
Day 2	Hamburger on bun Potato barrels Vegetable soup Sliced pineapple Whole milk	Cheeseburger on bun Potato barrels Vegetable soup Sliced pineapple with cottage cheese Oatmeal cookies Whole milk with 3 tablespoons of powdered milk added
Day 3	Lasagna Roll Tossed Salad Chilled pears Whole milk	Lasagna with extra cheese Roll Tossed salad with extra dressing Chilled pears Whole milk blended with pureed fruit

* A simple way to increase calories at mealtime is to add extra margarine to the meat, bread, soup or vegetables.

APPENDIX B

3. HIGH FIBER DIET

The following menu modifications show substitutions that can be easily made to increase the fiber content of the diet. Many high fiber foods are difficult to handle for children who have chewing or swallowing problems. Care should be taken to offer food that is appropriate for the child's feeding skills. If a child receives only strained or pureed foods the best way to increase the fiber content is to use unprocessed wheat bran mixed in or sprinkled on foods in controlled amounts. Remember that when fiber is increased, fluids should also be increased.

	Original Menu	Modified Menu to Increase Fiber*
Day 1	Country fried steak	Country fried steak
	Roll	Whole wheat roll or bread
	Whipped potatoes	Baked potato
	Peas and carrots	Peas and carrots
	Gelatin/topping	Oatmeal raisin cookies
	Whole milk	Whole milk
Day 2	Italian spaghetti	Italian spaghetti sprinkled with
	Roll	1 tsp unprocessed bran*
	Pan fried apples	Whole wheat roll or bread
	Tossed fruit	Pan fried apples
	Sunshine spice cake	Tossed salad
	Whole milk	Pear
		Whole milk
Day 3	Steak sandwich	Steak sandwich with lettuce &
	Roll	tomato
	French fries	Whole wheat roll or bread
	Peaches	Baked beans
	Whole milk	Fresh peach
		Whole milk

* When unprocessed wheat bran is added to recipes it should be used in limited amounts.

APPENDIX B

4. DIABETIC DIET

The following menus are examples of lunches that are possible substitutions for diabetic students. Each diabetic student should have a diet order from a physician which includes a meal plan and the number of snacks needed. The specific calorie level of the diet will determine which foods a student may eat and how much of each food is allowed.

	Original Menu	Modified Diabetic Menu
Day 1	Fish sticks Roll Macaroni and cheese Turnip greens Gingerbread with lemon icing Whole milk	Fish sticks Roll or plain macaroni Turnip greens Fruit cocktail, drained Graham crackers Whole or low fat milk
Day 2	Sloppy Joe on bun Hash brown patty Winter blend vegetables Fruit crisp Whole milk	Sloppy Joe on bun Winter blend vegetables Fresh fruit Whole or low fat milk
Day 3	Pork rib BBQ finger roll Whipped potatoes Peas and carrots Gelatin/topping Whole milk	Baked pork chop Roll Steamed carrots 1/2 banana Whole or low fat milk

APPENDIX B

5. PHENYLKETONURIA (PKU) DIET

Children with PKU must follow very restricted diets. They are not allowed to have high protein foods such as milk, meat, fish, chicken, cheese, nuts or beans. They may have limited amounts of medium protein foods such as bread, starchy vegetables, and fruits. They must drink a special formula called Phenyl-Free®. Some children may bring this formula to school and others may choose to drink it at home. **Appendix G. Phenylketonuria (PKU) Diet: Free Foods** provides a list of foods that the PKU child may eat for extra calories or for special treats. If a PKU student purchases lunch at school, he/she may require supervision to ensure the correct food selection.

	Original Menu	Modified Menu for PKU
Day 1	Italian spaghetti with meat sauce	1/4 cup spaghetti noodles 2 tbsp. meatless sauce
	Roll	1/2 cup green beans
	Green beans	1/2 cup fruit cup
	Apple crisp	8 oz. Phenyl-Free®
	Whole milk	Kool-Aid® or Hi-C® (optional)
Day 2	Corn dog	Tossed salad with Kraft® French dressing
	Greens	1/3 cup green beans
	Potato barrels	4 pieces potato barrels
	Applesauce	1/2 cup chilled pears
	Yellow cake with chocolate icing	1/2 cup applesauce
	Whole milk	1/2 cup sherbet
		8 oz. Phenyl-Free®
		Kool-Aid® or Hi-C® (optional)

	Original Menu	Modified Menu for PKU
Day 3	Tacos	Taco shell with 1/3 cup lettuce and 2 tbsp. taco sauce
	Mixed vegetables	
	Sliced peaches	1/2 cup peaches
	Chocolate cake	Apple (medium size)
	Whole milk	8 oz. Phenyl-Free®
		Kool-Aid® or Hi-C® (optional)

APPENDIX C

NUTRITIOUS SNACKS

1. High Calorie Snack Suggestions
2. Low Calorie Snack Suggestions

APPENDIX C

1. High Calorie Snack Suggestions

1 cup fruit flavored yogurt
1 cup fruit juice
1 cup sherbet
1 cup pudding
dried fruits: apples
peaches
raisins
apricots
cheeses, cubed or sliced
1 cup whole milk (instant breakfast mix may be added)
1 cup milkshake
1 cup ice cream
oatmeal cookies
crackers (add peanut butter or cheese)
toast (add peanut butter or cheese)
1/2 sandwich
1 cup cereal with milk

APPENDIX C

2. **Low Calorie Snack Suggestions**
(Each of these snacks provides 100 calories or less)

fresh fruit: apple
orange
pear
peach
1/2 banana
1/2 cup fruit juice
1 cup vegetable or tomato juice
3-4 plain crackers
2 cups popcorn without fat
1 hard cooked egg
1 ounce lean beef, chicken or turkey
carrot sticks
celery sticks
1 slice cheese
1/4 cup low fat cottage cheese

APPENDIX D

TEXTURAL MODIFICATIONS

RECOMMENDATIONS	EXAMPLES	NUTRITIONAL VALUE	PRECAUTIONS
1. To facilitate sucking and swallowing use pureed or soft foods.	Gelatin	High sugar Limited protein value	Avoid gelatin with fruit pieces.
	Pureed meats and vegetables	Good variety of vitamins and protein	Avoid using baby foods for extended periods of time.
	Pudding/ custard	High carbohydrates; milk provides calcium and protein	Tapioca pudding can be very offensive to hypersensitive children, and may provide extra stimulus to hyposensitive children.
	Applesauce	Low calorie High fluid content	
2. To facilitate sucking and swallowing use a heavy food that forms a bolus easily and gives proprioceptive input.	Mashed potatoes (excellent consistency for providing proprioceptive input)	High carbohydrate; adding margarine provides calories; adding powered milk adds protein and calcium	Mixing firm bits of food with mashed potatoes may not be tolerated by sensitive children; inconsistency in texture may cause choking.
	Oatmeal	High carbohydrate; milk adds calcium and protein	
3. Liquids may need to be thickened to improve and facilitate swallowing.	Liquids may be thickened with: yogurt, wheat germ, gelatin, cereal, carageen.	Yogurt: protein and calcium Wheat germ: carbohydrate and fiber Gelatin: see above Cereal: carbohydrate, vitamins (depends on the type of cereal)	Avoid high carbohydrates to thicken liquids; when food pools in the back of mouth, alternate with thinner liquids; avoid cornstarch.

TEXTURAL MODIFICATIONS

RECOMMENDATIONS	EXAMPLES	NUTRITIONAL VALUE	PRECAUTIONS
4. To first promote chewing use chewy or gummy foods that hold together to make a bolus.	Bananas Cheese Progress to: chicken, lunchmeat, marshmallows, soft vegetables, crackers, dried fruit fruit, apples zwieback toast, graham crackers	Fruits: carbohydrates and vitamins Cheese: protein and calcium Meat: protein Vegetables: vitamins and complex carbohydrates	Avoid food and meats that break apart; Avoid vegetables with skins unless well cooked.
5. To promote chewing when jaw is more stable, but movement is primitive, use crispy or harder solids.	Crackers Graham crackers Dried fruit	Crackers: complex carbohydrates Graham crackers: complex carbohydrates and fiber Dried fruit: high calorie carbohydrates	If you use carrots or beef jerky, avoid allowing child to bite off pieces. Use of tough meat may increase abnormal postures.
6. To desensitize the mouth grade the texture of the food; Use a blender if possible to make small variations in texture.	Begin with pureed, then progress to soft foods, then lumpy or solid.	Different nutrients can be provided in a variety of textures.	Do not begin with lumpy foods; a hypersensitive child will be intolerant of these; when blending foods avoid mixing all foods together.
Use a variety of tastes, textures, and temperatures.	Be creative given the above guidelines.	Variety should improve the nutritional balance.	Consult nutritionist, and occupational or speech therapist for advice.

* Oral-motor function should be evaluated by a qualified occupational therapist or speech therapist. The suggested interventions can be used in counseling the caregiver or child in conjunction with recommendations from the child's therapist.

Developed by J. Case-Smith and J. Horsley, 1986

APPENDIX E

JUVENILE RHEUMATOID ARTHRITIS DIET AND DRUGS

DRUGS	EFFECTS	POSSIBLE SOLUTIONS
Aspirin	Lowers the level of vitamin C in the the blood; increased vitamin C excretion	Provide a diet rich in vitamin C foods (citrus fruit, tomato, pepper, strawberry, potato); use pediatric supplements as recommended by physician.
	Stomach upset	Take with food.
IBURPROFIN Motrin® Rufen®	Nausea Indigestion Heartburn	Take with food.
NAPROXEN Naprosyn®	Nausea Indigestion Heartburn	Take with food.
FENOPROFEN Nalfon®	Nausea Indigestion Heartburn	Take with food.
TOLMETIN Tolectin®	Nausea Indigestion Heartburn	Take with food.
PENICILLAMINE Cuprimine® Depen®	Loss of taste or altered taste	Temporary side effect - hang in there!
	Poor appetite	Experiment with different foods; plan meals during highest appetite periods; serve calorie/ nutrient dense foods.
GOLD	Metallic taste in mouth; mouth sores	Experiment with different foods for tolerance (avoid very hot or very cold foods; avoid spicy, acidic and coarse foods). Try mouth wash with local anesthetic.

JUVENILE RHEUMATOID ARTHRITIS DIET AND DRUGS

DRUGS	EFFECTS	POSSIBLE SOLUTIONS
CORTICOSTEROIDS Cortisone Hydrocortisone Prednisone Prednisolone	Increased appetite, causing weight gain	Follow a weight management program with calorie controlled diet; monitor weight regularly.
	Sodium and water retention	Control sodium intake.
	Elevated cholesterol and triglycerides	Restrict fat intake (30% of total calories); follow a low cholesterol diet.
	Elevated glucose	Use the American Dietetic Association exchange diet.
	Possible osteoporosis	Review calcium and vitamin D intake and associated risk factors; use supplements as prescribed by physician.
METHOTREXATE	Loss of appetite	Experiment with different foods; plan meals during high appetite periods; serve calorie/nutrient dense foods.
	Mouth sores	Avoid salty, spicy foods; rinse with a local anesthetic.
	Diarrhea	Force fluids to avoid dehydration; avoid specific food intolerances.
	Folic acid deficiency	Supplement folic acid.

REFERENCES:

1. Arthritis Foundation, Arthritis Medication Brief, Questions and Answers about Penicillamine (Cuprimine, Depen), Atlanta: Patient Services Foundation, 1982.

2. Arthritis Foundation, Arthritis Medication Brief, Questions and Answers about Naproxen (Naprosyn), Atlanta: Patient Services Foundation, 1982.

3. Arthritis Foundation, Arthritis Medication Brief, Questions and Answers about Ibuprofen (Motrin, Rufen), Atlanta: Patient Services Foundation, 1982.

4. Henning, L.M., and Burrows, S.K.: Keeping up on arthritis meds. RN February:36-37, 1986.

5. Koenning, G.M.: Nutrition management of the child with juvenile rheumatoid arthritis. Topics in Clinical Nutrition 3(3):17-22, 1988.

APPENDIX F

COMPLICATIONS OF TUBE FEEDING

Problem	Possible Causes	Possible Solutions
Diarrhea	too rapid feeding too concentrated feeding formula intolerance lack of bulk in feeding bacterial overgrowth	• decrease feeding rate • dilute feeding, increase concentration gradually • add bulk to feeding as prescribed by physician • use cleanliness during preparation, storage, and administration • use anti-diarrheal agents as prescribed by physician
Constipation	inadequate fluid low fiber feeding lack of activity abnormal muscle tone medications	• increase free water • give prune juice • use a formula containing fiber • develop bowel management program • encourage ambulation when possible
Nausea, Cramping, Bloaing	cold feeding too rapid feeding delayed gastric emptying	• administer feeding at room temperature • decrease feeding rate • hold feeding until nausea stops
Vomiting	tube too large too rapid feeding feeding too concentrated	• use smaller tube • decrease feeding rate • dilute feeding, increase concentration gradually
Aspiration	reflux gag reflex large residual in stomach	• elevate head during and after feeding • thicken feeding • check tube placement
Weakness, Palpitations, Sweating	feeding too concentrated rate of feeding too high	• decrease rate of feeding • decrease concentration feeding, advance slowly
Obstructions	inadequate flushing poorly crushed medications poorly dissolved formula	• flush regularly • use liquid medications • use blender to mix formula • replace tube
Dehydration	excessive diarrhea	• increase free water

REFERENCES:

1. Robin, S., Thorp, J.W., and Wadsworth, C.: Tube Feeding of Infants and Children. Silver Spring: A.S.P.E.N. Publications, 1982.

2. Kostantinides, N.W. and Shrontz, E: Tube-Feeding: Managing the basics. American Journal of Nursing. September:1311-1320, 1983.

APPENDIX G

PHENYLKETONURIA (PKU) DIET: FREE FOODS

(These foods do not contain protein)

Popsicles (do not include Jello® gelatin or pudding pops, or juice pops)

Hard Candy (i.e. suckers, Lifesavers® , red-hots) (not the sugarless variety)

Brach's® Candies:
- Big Ben Jellies
- Butterscotch Disks
- Candy Corn
- Dessert Mints
- Jelly Beans
- Lemon Drops
- Orange Slices
- Root Beer Barrels
- Sour Balls

Bubble Gum (not sugarless)

Fruit Ices (not sherbet)

Hunt's® Lemon Snack Pack Pudding (lemon flavor only!)

Cotton Candy

Fruit Butters (apple, peach, etc.)

Honey

Jam, Jellies

Spiced Apple Rings

Beverages:
- Nondiet soda
- Apple juice
- Apple cider
- Tang®
- Country Time® drink mixes
- Lemonade, lime-ade from concentrate and powdered
- Kool-Aid® all flavors
- Start® drink mix
- Wagner® bottled drinks, all flavors
- Welch's® Sunshake bottled drinks
- Wyler's® drink mixes, all flavors